

Project Briefing

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Key points

- Barriers to accessing HIV-related services include travel costs, stigma, and the prioritisation of livelihoods over treatment
- Transfers for people on antiretroviral therapy between India and Nepal need to be formalised
- Cross-border NGO programmes are vital to ensure migrants can access care and support at home and at destination.

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Pathways to health services for cross-border migrants living with HIV: Nepalese and Bangladeshis at home and in destination sites in India

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Migration from Nepal and Bangladesh to India dates back decades, with many people moving to find better work and livelihood opportunities.¹ As they move they face risks, not least in relation to their health. As part of a five-year operations-research project, EMPHASIS (Enhancing Mobile Population's Access to HIV and AIDS Information Services and Support) has explored the health and HIV and AIDS-related vulnerabilities of migrants as they cross borders, and has provided targeted interventions at source, transit and destination sites (Sultana et al., 2011; Wagle et al., 2011; Samuels et al., 2012; Samuels and Wagle, 2011; Samuels et al., 2011).

This Project Briefing explores the experiences of people living with HIV (PLHIV) as they migrate. Drawing on small-scale qualitative studies in Bangladesh, India and Nepal (20 in-depth interviews in each country in the EMPHASIS project areas), we explore their migration experiences and their patterns of HIV diagnosis and treatment. We then provide examples of the barriers they face in accessing health services (including antiretroviral therapy {ART}, care and support services) at source and destination. This is followed by an outline of how EMPHASIS has addressed these barriers, and we conclude with some recommendations.

Migration experiences

Migration is an important coping and survival strategy for all respondents in the study. Having family on the other side of a border often influences migration decisions. While

people are pulled to migrate from Bangladesh and Nepal to India because of its livelihood potential, they may also have decided to move there because it is seen as a 'rite of passage' and because (for women) they followed their husbands there or because relatives promised to organise a good marriage for them.

Once in India, however, the reality did not always match their original ambitions. This was particularly so for female migrants who spoke of being forced by relatives to become involved in sex work, or being abandoned by their husbands to fend for themselves (this was the case at both source and destination locations). Others spoke of being trafficked, kidnapped and sold to brothels or pimps in India. Such experiences make women and girls particularly vulnerable to a range of risks, including contracting HIV.

These stories were particularly prevalent amongst Bangladeshi women who, perhaps because of the social norms that govern their lives, have limited opportunities to gather information and knowledge about the outside world. Such women, according to key informant interviews, are easily 'misled', particularly when they face extreme poverty or have been abandoned by their husbands. This, in turn, can lead them into the trap of being trafficked from Bangladesh to India, or while living in India, being forced into the sex trade (see Box 1).

Patterns of HIV diagnosis and treatment

A number of pathways can be identified through which migrants obtained HIV diagnosis and subsequent treatment.

Box 1: The migration story of a Bangladeshi woman

Ruma² has three children. Her husband left her and married for the second time after her third child was born. She migrated to India to survive, leaving her children in Bangladesh with her mother. She was forced to become involved in sex work in Mumbai, where she has lived for 10-11 years. Three years ago she had fever, allergy and headache. A local government hospital told her she had malaria and she was given injections, which she stopped as she fainted afterwards. Then she went to a private clinic, and was diagnosed as HIV positive...at the suggestion of the doctor there she enrolled herself in the Adhaar organisation, which helps HIV-positive people. With their help, she was admitted to Jyothi hospital (a community-care centre for people affected by HIV and AIDS, run by missionaries); there she had her CD4 test. Both Jyothi hospital and Adhaar asked for proof of residence in India. Then, with a reference letter from Jyothi, she was enrolled for ART in Dhirubai (private) hospital where they again asked for her proof of residence.

Migrants diagnosed at home who are being treated at home: The first pathway involved migrants, mostly men in Nepal and both men and women in Bangladesh, coming back to their home countries with a persistent illness, being diagnosed as HIV-positive in their home countries and being linked to domestic treatment, care and support services. A sub-set of Nepalese migrants, who were diagnosed at home and started treatment, supported by EMPHASIS, were given a transfer to an ART clinic in India and have since returned there.

Migrants diagnosed in India who are being treated at home: The second pathway represents migrants, again mostly men in Nepal and both men and women in Bangladesh, who were identified as HIV-positive in India but who later returned to either Nepal or Bangladesh and who are now being treated in their home countries.

Migrants diagnosed in India who are being treated in India: A third pathway represents those (both men and women) who had a persistent illness while in India, were diagnosed in India and are now obtaining treatment there.

Barriers to accessing and staying on treatment

Barriers to access

Stigma within the family and wider community remains an important barrier to accessing services. While stigma is decreasing, particularly in Nepal, fear of social exclusion and discrimination, still inhibits people from disclosing their status

and seeking treatment. This is partly because in all countries, particularly Bangladesh, HIV is still associated with marginalised groups or those seen as having 'deviant' behaviours, i.e. sex workers, men-who-have-sex-with-men (MSM) and injecting drug users. So-called 'normal' people, and in this case migrants, fear being associated with these groups and are reluctant to disclose.

Stigma from health service providers was also seen as a barrier: there were accounts of health service providers in Bangladesh declining to provide services (e.g. a caesarean-section delivery) upon learning the patient was HIV-positive. Similarly, in India respondents spoke about rude behaviour and denial of treatment on the part of service providers: 'As soon as health staff at the general health facility got to know that I am HIV positive, their attitude towards me has changed. It seems that their eyes were piercing my guilt even more' (male, Nepal).

Low levels of knowledge and understanding, plus misconceptions and fear also emerged as barriers, with one person even thinking, for example, that if they were found to be HIV-positive and sought treatment in Bangladesh they would be killed.

Barriers to staying on treatment

Travel costs were mentioned in all research sites in Nepal, India and Bangladesh as challenges that sometimes resulted in people discontinuing ART, particularly as most PLHIV come from low-income groups and the cost and time associated with travelling to a health centre represents a day of lost income.

Long waiting times were cited by many respondents. In Nepal (unlike Bangladesh) HIV-related services are provided, for the most part, through government facilities, but are not available every day. With ART provided only once a week and CD4 tests only twice a month, respondents spoke of long queues on these days. In India, shortages of staff caused long waiting times for those taking ART, resulting also in a day of lost earnings for themselves and the person accompanying them.

Accessing services from different points within a hospital and from different hospitals – In India people spoke of spending much time moving among different locations within hospitals or leaving without obtaining a particular service. In Nepal, as well as moving around within hospitals, they were also moved from one hospital to another, often at a considerable distance from their home: 'I first started ART in Dhangadi. Then I was transferred to Accham District hospital and now I am receiving ART from Bayalpata {community/non-government} hospital' (male, Nepal).

Inadequate or partial information from service providers – respondents in Nepal mentioned being transferred between different hospitals with no clear explanation for the transfer. Similarly, people in Nepal were not always provided with

Box 2: A circular migrant from Nepal

Maresh is a migrant worker in India. He came back to Nepal after his wife and daughter were diagnosed as HIV positive, and he was also later diagnosed himself. He is still a circular migrant. In total he has had a CD4 test 13 times. He complains that the hospital staff never provide the CD4 report to him. He is on cotrim, but not on ART (which he wants to start). He is not satisfied with the services, and thinks health workers should change their behaviour.

CD4 reports. According to one Nepali respondent in India he was only able to ‘navigate through my process of transfers from Nepal to India’ because he was literate (see Box 2).

Limited/one combination ART drugs. In Nepal only a limited combination of drugs is available – if a patient develops side-effects there is no alternative: either they have to continue or they have to quit.

Insufficient staff – this led not only to long waiting times, but also inadequate time for counselling and information provision. One female Nepalese respondent living in Mumbai, for instance, spoke about how the dosage was not explained properly and ended up consuming twice the daily dose, leading to severe illness, weakness and eventual hospitalisation.

Language barriers were faced by respondents in India (Mumbai), where hospital staff speak Marathi instead of Hindi. ‘I tried hard to find the ART centre in the hospital premises but couldn’t find it. I asked hospital staff as well but they spoke fast and in half Marathi, which I couldn’t understand. So I left without getting counselling done’ (male, Nepal).

Responses to barriers to access

EMPHASIS has introduced a number of interventions in response to some of the barriers faced by PLHIV both at source and at destination, particularly in relation to accessing testing, treatment and support services.

Voluntary Counselling and Testing (VCT) centres targeting potential migrants in Bangladesh. Building on suggestions from key informants and a wider government strategy to identify undocumented migrants as particularly vulnerable to HIV and in need of more programmes, EMPHASIS has supported the establishment of two VCT centres in government health facilities. Therefore, staff and training have been provided in Jessore and Satkhira – areas with high mobility between Bangladesh and India.

Referral and linkages to self-help groups within the same country. After the establishment of the VCT centres in Bangladesh, 17 of the 671 people who tested between May 2012 and March 2013 tested HIV-positive (all with histories of migra-

tion to India). EMPHASIS linked them to self-help groups. According to respondents, such self-help groups are critical in all countries in providing counselling, monetary and psychosocial support. EMPHASIS also helped to organise community sensitisation about HIV and AIDS and, more broadly, helped to alter the mindsets of both PLHIV and the communities in which they live.

Referrals to other programmes. EMPHASIS has linked PLHIV to other NGOs in India, particularly those providing critical nutritional-support services.

Transfers and referrals between source and destination. EMPHASIS has linked PLHIV to VCT and ART services, including self-help groups, between India and Bangladesh as well as between Nepal and India. This has allowed the continuity of treatment and the use of the same medication in all three countries (see Box 3).

Box 3 Transfers between Nepal and India

Jeet Singh has been living in Delhi since 1991. He was diagnosed as HIV-positive in a 2004 company medical check-up to get clearance to travel abroad. After learning about his status he returned to Nepal and encouraged his wife to do a test. She also tested positive. He started ART in Nepal. Later, he asked for a transfer letter from the Nepali ART health service centre so that he could access the same ART in India; he had to travel back and forth between Nepal and India many times before he could obtain the necessary letter. During that time he linked up with an EMPHASIS NGO partner in Delhi and with DNP+ (Delhi Network of positive People). With their help, he was finally able to access ART in India.

Recommendations

The recommendations arising from these studies reinforce on-going programme and policy work by EMPHASIS and others targeting policy makers in Bangladesh, India and Nepal.

- *Sustainable treatment, care and support services.* The extension of services beyond Dhaka, Bangladesh, requires support from the government to build staff capacity on HIV and AIDS-related treatment, care and support; provide further infrastructure and equipment; provide a one-stop service (i.e. all HIV-related services in one place); and ensure that services are non-discriminatory and confidential.
- *Extend drug regimens.* Although ART guidelines in Nepal contain different first- and second-line combination options, these are not available at all service centres. More options should be made available.



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- *Extend HIV-related service days in Nepal.* This would reduce the waiting time and allow greater uptake of HIV-related services.
- *Formalise cross-border ART transfer for Nepalese.* Given the friendship treaty between Nepal and India³, NACO (National AIDS Control Organization, India) and NCASC (National Centre for AIDS and STD Control, Nepal) could formalise transfers by establishing a referral system through the health facilities with a transfer protocol approved by both governments.
- *Continue project-based services for Bangladeshis.* Because no formal process can be developed, given the undocumented nature of most of these migrants, informal facilitation from NGOs should continue whereby cross-border NGO projects, such as EMPHASIS and the PLHIV networks, can link PLHIV in the two countries.

Given the priorities of migrants – primarily livelihoods and survival – many may be reluctant to start along the pathway to treatment. The time taken to get a HIV test and access treatment, for example, is a barrier to service uptake. It is critical, therefore, to link migrants to livelihood programmes. Increasing information and education in both source and destination countries about HIV and AIDS, as well as issues around treatment, care, support and positive living, will not only increase service uptake, but also help to tackle the fear, misconceptions and stigma that still surround HIV and AIDS.

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Endnotes

1. According to 2004 estimates, there are approximately one million Nepalese working in India (GoN, 2004). Although exact figures are unknown, the Indian 2001 census mentions there were approximately 3 million Bangladeshi migrants in India, representing 60% of total migrants.
2. To maintain confidentiality and anonymity no real names have been used in this briefing.
3. This bilateral treaty adopted in 1950 allows Nepalese and Indian to work across the border and be treated like native citizens.

Project information

These studies were conducted as part of Enhancing Mobile Populations' Access to HIV and AIDS Services, Information and Support (EMPHASIS). This is a five-year initiative funded by the Big Lottery Fund, UK, which is implemented by CARE in Nepal, India and Bangladesh. For more details, visit: www.care-emphasis.org